Intellectual & Developmental Disabilities Workgroup Minutes

Meeting #3
September 20, 2011, 10:00 am to 3:00 pm
United Way Conference Center
1111 9th Street, Des Moines, IA

MINUTES

Attendance

Workgroup Members: Jim Aberg, Ron Askland, Bob Bacon (Co-chair), Mary Dubert, Marsha Edington-Bott, Dawn Francis, Stephanie Gehlhaar, Jan Heidemann, Terry Johnson, Cindy Kaestner, Karalyn Kuhns (Chair), Roger Lusala, Mia Peterson, Susan Seehase, Dale Todd

Legislative Representation: Dave Heaton, State Representative, House District 91 (Henry County) and House Chair of the Health and Human Services Appropriations Subcommittee

Facilitators: Lilia Teninty, Human Services Research Institute (HRSI)

DHS Staff: Connie Fanselow, Jennifer Harbison, Deborah Johnson, Joanna Schroeder, Ken Tigges

Other Attendees:

Ronda Bennett	Iowa Department of Inspections and Appeals
Jess Benson	Legislative Services Agency
Marti Deluhery	Parent
Diane Diamond	DHS Targeted Case Management
Bob Emley	Grand View University
Kyle Frette	Easter Seals Iowa
Zeke Furlong	Legislative Services Agency
Bob Hebl	Discovery Living
Linda Hinton	Iowa State Association of Counties
Bonnie Kipper	Exceptional Persons Inc.
Sarah Lupkes	Polk County Health Services
Michelle Moore	Harmony House
Barbara Murphy	Harmony House

Marcy Murphy	SE Iowa Case Management
Sherri Nielsen	Easter Seals Iowa
Susie Osby	Polk County Health Services
Toni Powell	Exceptional Persons Inc.
Ann Riley	Center for Disabilities and Development
J. Mark Roberts	Lutheran Services in Iowa
Steve Roberts	Disability Rights Iowa

Other Attendees (continued):

Carol Warren	Progress Industries
Casey Westhoff	The Arc of Iowa
Dion Williams	Systems Unlimited
Ryanne Wood	Lee County CPC Administrator

Agenda

Agenda Topics:

- Introductory Remarks and Overview of Agenda
- Review of Information Requested from Performance Measures and Quality Management meeting
- Best Practices in Core Services, Trends in Service Delivery, and Iowa's current service array
- Group Discussion of Key Decision Points and Core Services
- Next Steps
- Meeting Summary
- Public Comment

INTRODUCTORY REMARKS AND OVERVIEW OF AGENDA

Meeting 3 Handouts:

- Meeting Agenda
- Overview of Best Practices in the Development of Core Services and Supports
- National Core Indicators and Data Sources Aligned with Three Home and Community Based Waiver Assurances
- Keeping the Promise: Self Advocates Defining the Meaning of Community Living
- Individual, Family and Systems Outcomes – DRAFT
- Measuring the Impact of Services to Individuals with Intellectual Disabilities Outcomes and Potential Data Sources

Additional Resources:

- CMS Informational Bulletin (Sept. 16, 2011): Updates to the §1915(c) Waiver Instructions and Technical Guide regarding employment and employment related services
- Iowa Administrative Code 441.77 – Outcome Information
- HSRI: What is Family Support?
- Advancing Integrated Employment Outcomes through Home and Community-Based Waiver Services

- Health Disparities Chart Book on Disability
- Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation
- Overview of 1915(c) Waiver Updates Regarding Employment Supports

Introductory remarks by Bob Bacon:

- Group has made good progress and appreciates the public comment that has been received.
- Series of five public meetings began last Friday.
- The turnout showed a lot of interest and attendees offered really good comments.
- The theme of many comments was individualized services and flexibility.
- It will be important to keep those themes in mind as we talk about core services.

OVERVIEW OF INFORMATION REQUESTED

- Overall the goal at the last meeting was to look at developing outcomes.
- Review of requests from last meeting:
    - Consolidated list of individual, family and system outcomes
    - Crosswalk of outcomes with potential data sources
    - Polk County performance monitoring and outcome tracking systems
- National core indicators tracked with CMS assurances.
- DHS is in the process of creating a new computer system that will greatly modernize IT for Medicaid.
- Reviewed annual report from DHS Targeted Case Management.
- We may not have identified yet all the system outcomes that need to go along with the individual outcomes.
- We talked about going from a strict ID definition to a DD definition that will encompass autism and other developmental disabilities.
- A great deal of waiver services are delivered in 16 or less waiver bed settings that DIA oversees; we have not really talked about that.
- The October 18 meeting will address provider qualifications and monitoring.
- Today's goal is to identify a statewide and consistent service array.

OVERVIEW OF BEST PRACTICES IN THE DEVELOPMENT OF CORE SERVICES AND SUPPORTS

Service coordination:

- Independent advocate for the individual.
- Can express wishes and goals of person and family.
- Knowledgeable about state and local resources.
- Ability to navigate the system.
- Can facilitate the process from a person-centered perspective.
    - Identify goals
    - Help select qualified service providers
    - Support individual in self-directing

    - Assess and develop plans to address identified areas of risk.
    - Monitor service delivery and the well being of the individual.
    - Function as the first point of quality assurance.
- Apply knowledge of the person and the system to develop appropriate transition plans.

Group Discussion of Service Coordination:

- Affordable Care Act presents some opportunities.
- One significant aspect is conflict free case management that is not tied to the source of funding or service providers.
- How will there be fiscal control over how much money is spent?
- The State would ultimately be responsibility for monitoring and making sure individual goals are met.
- Some states tie assessed need to the dollar amount available for services, then the case manager is responsible for how that budgeted amount is best spent for the benefit of the person.
- Targeted case mangers have a cap on number of cases, other case managers or service coordinators don't.
- We need to know how much additional manpower would be needed for that kind of individual case management.
- If other waivers are folded into the ID waiver, it might allow more federal dollars to be drawn down for Targeted Case Management.
- Addressing the issue of the independence of case management is an integral part of qualifying for potential enhanced Medicaid match.
- It is one of a number of things the state would have to implement to qualify for the enhanced match rate through the Balancing Incentives Payment Program (BIPP).

Family Support:

- Family driven – the family leads the decision making process in service planning.
- Easy to use – families are not overwhelmed by paperwork and complexity.
- Flexible – families can choose services and supports according to their needs and preferences.
- Types of Family Support:
    - Respite
    - Family to Family mentoring
    - Crisis prevention and support
    - Counseling services

Group Discussion of Family Support:

- In the past, a lot of states funded these types of service with non-Medicaid dollars.
- Now more and more are being rolled under the Medicaid umbrella.
- There is some challenge with making the services flexible enough to support the family while keeping them focused on the Medicaid-eligible individual's needs.

- Respite is a low-cost service that makes sense as a non-Medicaid service to support people who are waiting for Medicaid services.

Community Living:

- Is outcome driven.
- Supports community integration.
- Emphasizes the unique characteristics of the person.
- Includes options for self-direction.
    - The authority to pursue the vision of the individual and family.
    - Valued roles for individuals and families.
    - Access to quality support options.
- Members were asked to read "Keeping the Promise: Self Advocates Defining the Meaning of Community Living."
- A really compelling perspective on community living by self-advocates.
- No matter the size of living arrangement, segregation is not community.
- Gated communities exclusively for people with disabilities are not really community.
- HCBS puts people in the community, but doesn't always achieve their community living goals.

Employment Services:

- Vision is for a "work first" policy including:
    - Wages at or above minimum wage
    - Appropriate benefits
- Job development
    - Identification of steps to assist the person achieve integrated employment
    - Time limited with a specific outcome
- Prevocational
    - Time-limited – not the end point or goal
    - Focused activities leading to competitive employment
    - Including volunteer and other unpaid activities
- Support Employment
    - Individual
    - Group

- New CMS Informational Bulletin released just yesterday explains how CMS is approaching the reviewing §1915(c) Waivers regarding employment and employment related services.

Average hourly wage by residence type:

- Institution - $4.71
- Community-based residence - $6.96
- Independent home or apartment - $7.04
- Parents' or relative's home - $7.71

Group Discussion of Employment Services:

- Pre-vocational means “no-vocational” to many consumer advocates.
- Not really making progress toward competitive employment.
- CMS indicates states may start putting a time limit on what is “pre-voc.”
- If we start from the expectation that everyone can work, then we are going to get more of the people who can work in competitive employment.
- If we start from the expectation that not all people with disabilities can work, then we are not going to get everyone who can working competitively.
- There should not be a hard and fast timeline for pre-voc, but reasonable expectation of progress.
- We should think of it in terms of developing services that are individualized and focused on the person’s needs.
- We have the traditional mindset of employment meaning a 40 hour work week, but appropriate work for some may be a part time job, not full time.
- A case manager with the help of the person’s team should be working to determine what the person wants to do, what are realistic goals and realistic time frames for reaching them.
- Socialization in pre-voc activities may be very important for people who are not yet ready for competitive employment.
- It is clear that the federal government is moving in the direction of giving people with disabilities a chance for competitive employment.
- People with ID/DD living on their own and working can be very successful, but may occasionally need help with advocacy or other aspects of their lives.
- Some people may need more help in other areas.
- The Medicaid buy-in program helps by allowing people to earn more money and continue Medicaid coverage on a sliding scale.

Health and Primary Care:

- Must be able to meet the needs of people with ID/DD.
- Must be available in local communities throughout the state.
- Needs to include a variety of services:
    - Effective diagnosis and clinical evaluation
    - Access to general health screenings and primary care
    - Care coordination
    - Behavior support services
    - Psychiatric and counseling services
    - Occupational and Physical Therapies, and Speech-Language services
    - Medication management and self-administration training
    - Dental services

Health and Primary Care statistics:

- 40% of people with disabilities report their health as fair or poor compared to 23% of the general population.
- National Core Indicator (NCI) data for 2009-10 shows:
    - 84% had a routine dental exam in the past year
    - 65% had a vision screening in the year
    - 75% had a hearing test in the past 5 years

    - 54% of women had a Pap test in the past year
    - 84% of women over 40 had a mammogram in the past 2 years
    - 59% of men over 50 had a PSA test in the past year
    - 23% of people age 50 or older had a colorectal cancer screening in the past year
    - The highest proportions of sedentary people are those with disabilities (37%)
    - Inactivity is strongly linked to obesity; 30% of people with disabilities are obese
- NCI data indicates only 23.6% of people with ID engage in at least moderate physical activity.
- NCI data shows a link between the level of ID and obesity.
- NCI data shows high use of psychotropic medication.
- Use of psychotropic medications is strongly linked to obesity and health problems when used long term.

Group Discussion of Health and Primary Care:

- It is very helpful for students in medical school to learn specifically about serving people with DD.
- Many CMHCs are already serving people with ID/DD.
- Services need to include ID/DD co-occurring with mental health, multiple disabilities, and/or substance abuse.

Crisis Prevention and Intervention Services should be:

- Community based
- Responsive statewide with 24-hour access
- Available to families and providers
- Based on Positive Behavioral Supports
- Specialized to support people with ID and those with dual diagnosis (MI/ID)
- Inclusive of system-wide, on-site training

Group Discussion of Crisis Prevention and Intervention:

- Propose recommending that crisis teams be trained to meet the needs of all populations they may see.
- That is another aspect of co-occurring capability.
- Iowa currently has the IPART team.

National Trends:

- Show growth in community services and more people living at home in family settings.

Iowa Trends:

- Look a little different.
- Highest number shows other HCBS residential, then family home.

- Iowa data doesn't track adults living in the family home, so the "other HCBS" numbers probably represent adults and the "family home" numbers likely represent children.
- Data can look different because of the ways states track it.
- It was also noted at an earlier meeting that Iowa is serving more people but at a lesser cost than many other states.
- It can be challenging for adults with ID/DD to live with families and still exercise the kind of independent decision making they want.

Iowa's Current Service Array: (the most commonly used ID waiver services and number of people receiving each type of service)

- Supported Community Living (daily) – 3797
- Supported Community Living (hourly) – 4336
- Supported Employment (job coach) – 819
- Supported Employment (enclave) – 588
- Prevocational (daily) – 779
- Prevocational (1/2 day) - 837
- Prevocational (hourly) – 174
- Day habilitation (daily) – 1312
- Day habilitation (1/2 day) – 1940
- Respite – 3961
- Transportation – 1221

Mandated and County Funded Services:

- Information and Referral
- Consultation
- Public Education Services
- Case Management
- Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD)
- State Hospitals
- Commitment:
    - Diagnostic evaluations related to commitment
    - Sheriff transportation
    - Legal representation for commitment
    - Mental Health Advocates

- Some of the services listed above are not directed at people with ID/DD.
- Some, such as commitment, may require a secondary diagnosis.

Looking beyond Medicaid to a "three-legged" approach:

- Individual supports – networking with one another and sharing resources
- Community supports
- Government
- Reflects good best practice and financial reality
- Recognizes need to rely on community level, non governmental supports to supplement public services

The importance of Holding Providers of Services and Supports Accountable for Outcomes:

- Looked at outcomes first and now moving on to core services.
- Agreeing on desired outcomes is easy step.
- Harder to develop monitoring and discovery processes hat measure whether or not outcomes are present for individuals and families served.
- Unless you measure it, you won't know if outcomes are achieved.

Key questions to be discussed:

- How does the current service array align with best practice?
- Does the service array support preferred outcomes for individuals, families and the system?
- Are there gaps in Iowa's core service array for people with Intellectual Disabilities? For their families?
- How can they be addressed?
    - Short-term
    - Long-term
- Are there services the workgroup recommends phasing down or out?
- Are there new services that need to be added or current service options that the workgroup recommends expanding?
- Given scarce resources, which services, either currently in place or recommended to be in place, should be prioritized for implementation?

Goal for today's meeting:

- List of generally agreed on core services for people with ID/DD.

GROUP DISCUSSION OF CORE SERVICES RECOMMENDATIONS

- The group identified individual and family outcomes and may need to consider system outcomes as well.
- Talked about Telehealth to stretch resources, especially for access to Psychiatrists.
- There is a push nationally for a "no wrong door" approach so that people can make informed choices whether they are Medicaid-eligible or not.
- Iowa has the ID waiver that currently includes a number of services.
- We should consider those current services, but not be limited by them.
- What are the services we want people in Iowa to have?
- We may have to prioritize them or phase them in over time, but for this discussion we should not be constrained by how we are going to pay for what we think people should have.

Areas to discuss:

- Service coordination/case management

- Employment services
- Technology

How does the current service array align with best practice?

- ID waiver
- County funded services
- I & R services
- ICFs/MR

POTENTIAL RECOMMENDATIONS FOR CORE SERVICES

- Should be driven on Olmstead principles.
- What are the “must haves” and the “would like to haves”?
- Some components may need to be phased in over time.
- Iowa has a lot of flexibility in the Waiver.

- Crisis prevention and intervention services:
    - There is a draft set of waiver rules being developed around behavior support and crisis intervention.
- Employment:
    - Idea of career development
    - Identifying skills and resources
    - Supported employment – supporting the person on the job; may be in competitive employment
- Behavior support services:
    - IPART
    - Can now be built into SCL as another support service (consulting).
- Co-occurring capability:
    - Treatment for co-occurring and multi-occurring conditions including mental health conditions and substance abuse.
- Transition services:
    - from children’s to adult system
    - from setting to setting
- Occupational Therapy (OT), Physical Therapy (PT), and speech not otherwise covered by State Plan because it is not rehabilitative, but to maintain and improve functioning
- Dietician/nutrition services
- Recreation services and supports
- Residential services:
    - Residential services with daily SCL
    - In-home services with hourly SCL
    - ICFs/MR
    - RCFs/MR can now receive waiver dollars; should RCFs be included?
- Nursing services:
    - EPSDT pays for 16 hours per day of private duty nursing.
    - That goes away when a person becomes an adult.

    - Then there are not enough dollars under the waiver to pay for similar care.
    - Waivers have to be cost neutral; no more than the cost of a nursing facility.
    - A high level of need for nursing services may be more than that.
- Day care/day services for adults with DD ("day care"); day services for retirement aged people:
    - Dislike the term "adult day care" currently used.
    - Legislature could look at that language distinction to be more respectful to older adults.
- Transportation services:
    - Transportation is also an employment issue.
- Housing services
- Set-up costs to establish a household
- Modifications/environmental supports
- Wrap-around services:
    - For needs that don't fit other categories (examples: rent assistance; paying registration for Y-membership).
    - The Conner fund could be a precedent for a state pot of funds for wrap around.
- Consider all services currently available on the ID waiver
- Attendant care services/Consumer Directed Attendant Care
- Respite
- Mental health outreach
- Case management/service coordination
- Day programs:
    - Prevocational/job readiness training – preparing for employment
    - Job development
    - Supported employment
    - Day habilitation
- Peer support/Family Support/Self-advocacy support
- Align with MH peer support?
- Explore the idea of behavioral health home with a person-centered team?
- Technology:
    - Telehealth to increase access
    - Information and referral (ADRC)
    - Assistive technology

Discussion of sheltered workshops:

- Should we include sheltered workshops?
- Counties are now paying for sheltered work.
- We rely heavily on sheltered work now; how do we move to more supported employment?
- Do we identify the services that are the direction we want to go?
- And also acknowledge that we can't get there right away; it will be a process.
- Even small amount of income and the value of working is important to many people now doing sheltered work.

- We don't want people pushed out of sheltered work into day habilitation rather than supported employment.
- We don't want people disqualified from prevocational services too soon because they will miss out on opportunities for job readiness training.
- Iowa does not incent supported employment.
- Medicaid is the single largest funder of employment services in the U.S.
- SELN analysis has shown that about 80% of Iowa employment dollars go to work activity/sheltered workshop activities.
- Providers report using income from sheltered work to help pay for the provision of supported employment services.
- There is no good flow for getting people out into employment.
- There aren't enough referrals to support the staff needed to assist people in getting employment.
- Work services should be focused on getting people to the point they are employable.
- If it is truly a "service," it should be focused on how to get people employed.
- We can't lose sight of the fact that even for persons working at sub-minimum wage, their income may mean the difference between integration or not.
- We can't lose sight of realities of life; jobs are very scarce, especially in rural areas.
- Sheltered work may not be an ideal choice, but it may be the best one available.
- Some community employers work with sheltered work contracts because they feel it is the right thing to do.
- We want people to have productive activities during the day and need to offer an array.
- Sheltered workshops are a big piece of that array right now.
- We can work on incentivizing a shift to more competitive employment over time.
- Supported employment is also sometimes at sub-minimum wage.
- We want something for everybody who is capable to be productive during the day.
- Don't want those who are not capable of or ready for competitive employment to be left out.

Discussion of Case Management/Service Coordination:

- What should it look like?
- What are the functions?
- A local service access process
- Eligibility determination – diagnostic, functional, financial, and annual re-determination
- Assessment of need – might want someone else to do SIS?
- Consumer directed service
- Care planning & Risk assessment
- Referral to provider services
- Monitoring of services
- Case management should be independent; serve as advocate
- Who should be gatekeeper to review and authorize services?

- Doing both would place CM in a difficult position

Issues to be referred to other workgroups:
- Day care services for children with special needs.
- Adding attendant care to the State Plan services.
- Rates employment study funded through MIG.
- Setting reasonable case management caseload caps.
- IVRS involvement in employment for people with DD.
- It takes interagency efforts to make some kinds of changes happen.

Discuss next time in workforce development:
- Workforce qualifications needed to provide behavioral and/or intense services.

NEXT STEPS

For next meeting:
- Will put core services preliminary recommendations into service array grouping.
- Val Bradley will facilitate discussion of workforce development issues.
- First three meetings have covered eligibility, outcomes, and core services.

NEXT MEETING

The next ID/DD Workgroup is scheduled to meet on Tuesday, October 4, 2011 from 10:00 am to 3:15 pm at the United Way Conference Center, 1111 9th Street, Des Moines, IA.

Meeting 4 Agenda Topics:
- Best practice and trends regarding workforce
- Workforce key decision points
- Workforce workgroup recommendations

MEETING SUMMARY

Emerging Areas of Consensus:
- Senate File 525 wisely used the language of “core services and other support,” which allows options for flexibility and is in the spirit of Olmstead and best practice.
- There should be an array of services that are available as a menu to meet individual needs with flexibility.

Preliminary Core Service Priorities:
- Community based
- Services that are included in the ID Waiver
- Services that are to be added to the ID Waiver
- Co-occurring capability
- One time cost for transition/household set-up (now covered under MFP)

- Therapies beyond rehabilitation
- Housing
- Transportation
- Service coordination
- Day services
- Employment

PUBLIC COMMENT

Comment: I come from a mental health and substance abuse background and this doesn't look a lot different. Family counseling is never covered in by insurers, yet many people live in their family environments. Adults in their 40s and 50s are still coming into the system as their parents age who have never received services. The system will need to expand to meet the need. We have a long way to go in co-occurring treatment. Substance abuse doesn't "see" mental health and neither "sees" intellectual disability. We need to address pulling all those separate pieces together. The system is punitive towards long-term care. I work for a provider with a 62 bed unit that offers excellent services, but we are going to close if we don't get a better pay rate and the people we serve are not going to be going into the community.

Comment: Please consider including guardianship and conservatorship in the core services. There is a big need in our part of the state for guardians and conservators to prevent neglect and financial exploitation. You might also consider that a goal of sheltered work is integration.

Comment: There are instances where sheltered workshops have been abused, but that doesn't mean we need to change the whole structure. We need to support everyone at the level they are at and make sure that the services are appropriate for the person, but we should not get rid of sheltered work as an option. We should support service integrity. Please try to make core services "diagnosis neutral;" don't have a different rate for different people or groups accessing the same service.

Comment: Transition services for young people moving from children's to adult services are important. For children currently in foster care, allow continued Medicaid coverage from MEYA (Medicaid Extension for Young Adults). Kids coming from PMICs or the Children's Mental Health Waiver into the adult world need that ongoing support after foster care.

Comment: When you talk about transition services, please remember that for adults there are a lot of transitions and they are often very difficult –

job changes, discussion of residential change, staff changes, are all stressful and significant transitions for some adults with ID/DD and it may be necessary to ramp-up services at those times.

Comment: Please consider supported education as a core service. We should all think of ourselves as life-long learners. I'd also like to suggest incorporating public comment after each agenda item, so it can more closely follow the topics discussed.

Comment: If we are talking about service coordination for all people with ID/DD, not just those on Waivers, then we should talk about independent advocacy for them in all settings. The concept of service coordination may be the same in all settings, but the mechanism is different for people in ICFs/MR; they should have advocates assisting with their service coordination.

Comment: What is the definition of a community provider? Woodward and Glenwood State Resource Centers are serving about 470 people. They are 2 of 141 providers in the state. Are the remaining 139 all community providers? All ICFs/MR deal with individuals who have difficult behaviors.

For more information:

Handouts and meeting information for each workgroup will be made available at: http://www.dhs.state.ia.us/Partners/MHDSRedesign.html

Website information will be updated regularly and meeting agendas, minutes, and handouts for the six redesign workgroups will be posted there.